



National Institutes of Health
National Human Genome Research Institute
Office of Rare Diseases

10 Center Drive - MSC 1851
Building 10, Room 10C103
Bethesda, Maryland 20892-1851

Undiagnosed Diseases Program

Dear Patient:

Thank you for your interest in the Undiagnosed Diseases Program at the National Institutes of Health (NIH). Participants accepted into this program will be part of a clinical research study aimed at answering questions about medical conditions that have eluded diagnosis. We hope to advance medical knowledge in ways that can help improve health care for everyone. The study will be conducted at the NIH Clinical Center in Bethesda, Maryland.

Please discuss your participation in this program with your primary health-care provider. Important considerations include:

- This is a pilot program with strict eligibility requirements.
- Many cases accepted will NOT result in a diagnosis.
- A referral by a health-care provider is required.
- The provider who refers you will be asked to provide your medical information.
- NIH will communicate the decision on accepting your case for evaluation in writing to you and your referring health-care provider.
- If your case is accepted for NIH evaluation, NIH will provide information from the evaluation to you and to your health-care provider.
- Your health-care provider will be responsible for your medical care after you have been evaluated at the NIH.

Details about the information needed from your referring physician are on the attached letter. Please insert information where requested and give the *Information Sheet for Referring Health-Care Providers* to your provider.

NIH program staff will notify you by mail when the information from your provider has been received. Once all materials are received, NIH review is expected to take about six weeks. We plan to invite 50 to 100 patient participants to NIH annually for thorough evaluation and consultation at the NIH Clinical Center.

Again, thank you for your interest in this new NIH program. Medical advances depend on individuals like you who volunteer as partners in medical discovery. More information about this new program is available on line at <http://rarediseases.info.nih.gov/Undiagnosed>.

The Undiagnosed Diseases Program Team

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